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GLOBAL ONCOLOGY: RESEARCH ARTICLE

"Money was the problem": Caregivers' self-reported reasons for abandoning their children's cancer treatment in southwest Uganda

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Abstract

Introduction: Treatment abandonment contributes significantly to poor survival of children with cancer in low- and middle-income countries (LMIC). In order to inform an approach to this problem, we investigated why caregivers withdraw their children from treatment.

Methods: In a qualitative study, carried out in October and November 2020, in-depth interviews were conducted with caregivers of children who had abandoned cancer treatment at the Pediatric Cancer Unit of Mbarara Regional Referral Hospital in southwestern Uganda. Recorded in-depth interviews were transcribed and analyzed to identify themes of caregivers' self-reported reasons for treatment abandonment. The study was approved by the Review and Ethics Committee of Mbarara University of Science and Technology.

Results: Seventy-seven out of 343 (22.4%) children diagnosed with cancer abandoned treatment during the study period; 20 contactable and consenting caregivers participated in the study. The median age of the caregivers was 37 years and most (65%) were mothers. At the time of this study, eight (40%) children were alive and five (62.5%) were males; with a median age of 6.5 years. Financial difficulty, other obligations, the child falsely appearing cured, preference for alternative treatments, belief that cancer was incurable, fear that the child's death was imminent and chemotherapy side effects were the caregivers' reasons for treatment abandonment.

Conclusions and recommendation: Seeking cancer treatment for children in Uganda is an expensive venture and treatment abandonment is mainly caused by caregivers' difficult socio-economic circumstances. This problem needs to be approached with empathy and support rather than blame.

KEYWORDS
cancer, children, financial difficulty, low- and middle-income countries, treatment abandonment, Uganda

Abbreviations: HIC, high-income country; LMIC, low- and middle-income country; MRRH, Mbarara Regional Referral Hospital; UCI, Uganda Cancer Institute.

1 | INTRODUCTION

Treatment abandonmentis defined as the failure to either begin or complete cancer therapy that would cure or contain the disease and/or missing treatment appointments for ≥4 consecutive weeks that impacts on the ability to cure or contain the disease.[1,2] It is recognized as a major contributor to therapeutic failure in pediatric cancer patients[3–6] and is particularly a challenge in low- and middle-income countries (LMICs) where only 10%–20% of children diagnosed with cancer are cured compared to the 80% in the high-income countries (HICs).[7,8]

Treatment abandonment rates average 3% in HIC and 30% in LMICs and are predicted by lower Gross National Product per capita, absence of national health insurance schemes, and high prevalence of economic hardship.[9] Other predictors include, low socio-economic status, poor literacy, increased travel time to hospitals, and lack of affordable local treatment.[10–12] Caregiver self-reported reasons for treatment abandonment in LIC include, among others, financial constraints, misplaced incurability of cancer, false perception of cure, preference for alternative medicine, fear of adverse treatment effects, and perceived poor prognosis for cancer.[3,4,9,13,14]

In Uganda, a study done at Uganda Cancer Institute (UCI) showed a treatment abandonment rate of 33% among all children diagnosed with cancer,[15] but a subsequent one of children diagnosed with Burkitt lymphoma at the same institution found a rate of 10%, but the reasons for abandonment have not been studied. Cancer diagnosis and treatment at the Pediatric Cancer Unit (PCU) of Mbarara Regional Referral Hospital (MRRH) are provided free by the Uganda government and philanthropy. However, one in every four children diagnosed with cancer does not start or complete therapy.[16] This study was therefore designed to find out why caregivers at our unit abandon therapy in order to design mitigating interventions for this problem.

2 | METHODS

2.1 | Study setting

This study was conducted at the PCU of MRRH, located in Mbarara City, south-western Uganda, 260 km from the capital, Kampala. The PCU is a 16-bed capacity ward and an outpatient clinic. It is one of the four pediatric cancer treatment facilities in Uganda and the only one in south-western Uganda, serving a population of about 6 million people.[17] On average, 120 children (aged below 16 years) are enrolled into care with newly diagnosed cancer annually (unpublished PCU medical records).

At the unit, all caregivers, upon a new cancer diagnosis of their child, have a private counseling session with a pediatric oncologist. During this session, the diagnosis of the child is revealed, the treatment plan discussed, the side effects of the treatment revealed, and the child's expected chances of survival explained. Caregivers who abandon treatment are immediately followed up with phone calls from the clinic staff until either they return, indicate they are not willing to return, or reveal that the child is dead.

2.2 | Study design

We conducted a qualitative study, in October and November 2020, of caregivers whose children had been diagnosed with cancer from May 2017 to August 2020 and abandoned treatment. Telephone contacts of the caregivers of children who abandoned treatment were retrieved from the medical records. Telephone calls were made to them to make appointments for home visits, without revealing the reason for the visit. The research team visited the caregivers who accepted the home visits and conducted in-depth interviews with them.

Prior to the interviews, the caregivers provided written informed consent to participate in the study and to have their responses tape-recorded. Interviews were conducted by two research assistants in the commonly used local language and recorded with tape recorders. One research assistant interviewed the caregiver and the other took notes about his/her nonverbal communication. Each interview took about 60 minutes and a maximum of four interviews were conducted each day. Team debriefing sessions were held the day after the interviews to discuss the important findings from the data collected.

The recorded interviews were transcribed verbatim for analysis. Data were analyzed using NVivo software (version 12, QSR International, Burlington, MA). Thematic content analysis was used to analyze the data and a code book was generated comprising all of the major themes. The emerging themes were organized into an explanatory logic that provided a succinct conceptual model of reasons for treatment abandonment. The research proposal was approved by the Review and Ethics Committee of Mbarara University of Science and Technology (MUST) (39/01-20).

3 | RESULTS

Three hundred forty-three children below 16 years of age were diagnosed with cancer from May 1, 2017 to September 30, 2020, and 77 (22.4%) of them abandoned therapy. Sixty-eight of those who abandoned therapy (88.3%) had some chemotherapy, while nine (11.7%) did not start treatment. The phone contacts of 51 out of these 77 caregivers were either not available (22), persistently switched off (25), or calls were answered by someone who claimed not to know the child in question (4). Caregivers of 26/77 (33.8%) children were reached by phone to request a home visit by the research team and 20 (76.9%) accepted, as shown in Figure 1.

3.1 | Demographic characteristics of caregivers

The demographic characteristics of the primary caregivers are shown in Table 1. Their ages ranged from 24 to 65 years, with a median age of

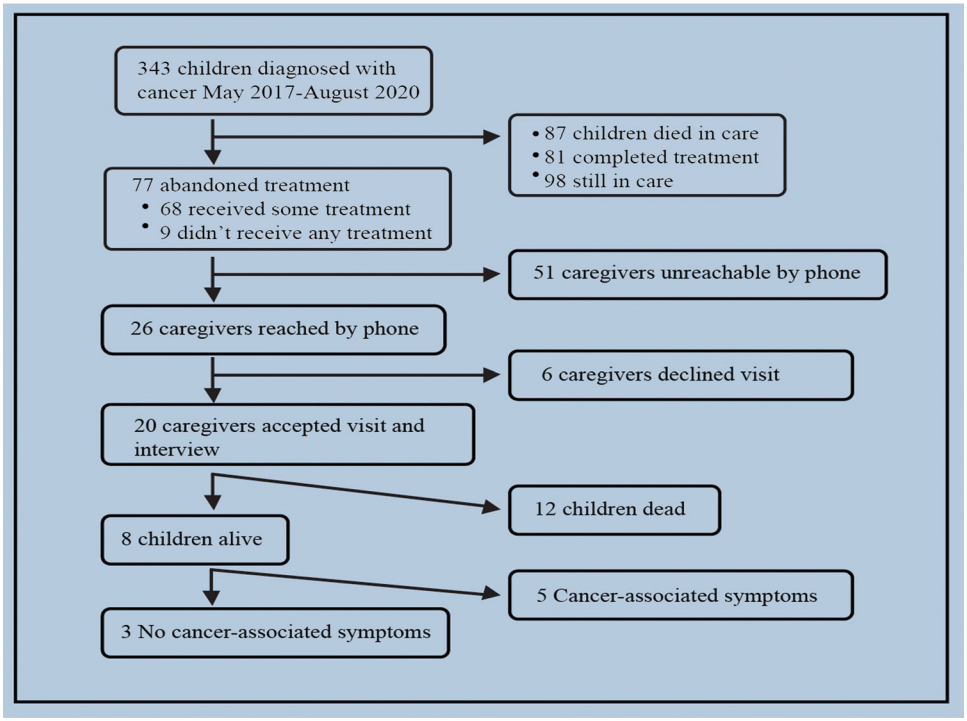

FIGURE 1 Caregiver tracking schema

TABLE 1 Demographic characteristics of caregivers who abandoned treatment

Characteristics	*n*	%
Caregivers' age (years), median (range)	37 (24–65)	
Marital status, married	18	90
Relationship with child		
Mother	13	65
Father	7	30
Grandfather	1	5
Address (district)		
Mbarara	4	20
Isingiro	4	20
Ntungamo	3	15
Ibanda	2	10
Ibanda Sheema	1	5
Rwampara	1	5
Bushenyi	1	5
Mitooma	1	5
Sembabule	1	5
Kamwengye	1	1
Kazo	1	1
Employment		
Farmer	15	75
Other	5	25

TABLE 2 Demographic and clinical characteristics of living children who abandoned treatment

Characteristics	*n*	%
Children's age (years), median (range)	6.5 (4–15)	
Sex, male	5	63
Diagnosis		
Nephroblastoma	2	25
Hodgkin lymphoma	2	25
Lymphoblastic lyphoma	2	25
Acute lymphoblastic leukemia	1	13
Chronic myeloid leukemia	1	13

37 years. Thirteen (65%) were the children's mothers, six (30%) were their fathers while one (5%), a grandfather. The children of eight (40%) caregivers were alive, whereas those of 12 (60%) had died.

3.2 | Demographic and clinical characteristics of the living children

The demographic and clinical characteristics of the eight children who were still alive at the time of the study are shown in Table 2. Their ages ranged from 4 to 15 years, with a median age of 6.5 years, and five (62.5%) were males. Their diagnoses were as follows: two nephroblastoma, two Hodgkin lymphoma, two lymphoblastic lymphoma, one chronic myeloid leukemia, and one acute lymphoblastic leukemia. Three (37.5%) had cancer-associated symptoms.

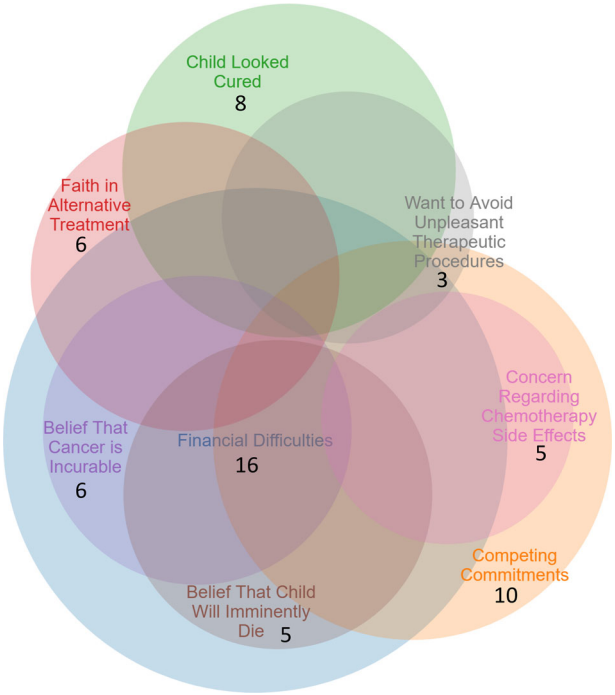

FIGURE 2 Venn diagram showing the caregivers' reported reasons for abandoning their children's cancer treatment

3.3 | Reasons for treatment abandonment

Several important thematic reasons for treatment abandonment emerged from the in-depth interviews with the caregivers who had withdrawn their children from care and are shown in Figure 2 and Table 3.

Financial difficulty was, overwhelmingly, the most commonly cited reason for treatment abandonment. Caregivers reported experiences of struggling to raise money to buy food and other necessities during the often prolonged and repeated hospital stays that characterize cancer treatment.

> "My husband used to borrow money from a saving group, which we're still paying back up to now. One time when I called him, he told me he didn't have money and that I should take the child home," said caregiver number 15, tears running down her cheeks.

Some caregivers reported selling their property to meet the repeated costs after which they had nothing else to sell.

> "For us, we did our best. We sold almost everything, including goats, cattle and even land. After that, we did not have any more money and gave up. So, money was the problem," said caregiver number 9, folding her arms and beginning to cry.

Money was also required for transport to repeated hospital visits. When caregivers could not raise money for transport anymore, they stopped coming.

> "We did not go back because we failed to get money for transport; haven't you seen that our place is very far?" said caregiver number 6.

Caregivers reported feeling conflicted about exhausting all the money on one sick child at the expense of the needs of the other children and family members.

> "The father had a small piece of land and we considered selling it but wondered where we would put the rest of the children. We therefore decided to leave him," said caregiver number 19.

TABLE 3 Summary of caregivers' reasons for treatment abandonment

Theme	Description	Frequency
Financial difficulties	When caregivers lacked money for transport, upkeep, investigations, and other treatment-related expenses	16
Competing commitments	When caregivers had other obligations competing for their limited time and resources	10
Child looked cured	When caregivers falsely thought that the child looked well and the illness was no longer a priority	8
Faith in alternative treatment	When caregivers preferred and trusted other forms of treatment than medical care	6
Cancer is incurable	When caregivers believed that cancer is not curable and considered its treatment a waste of time and resources	6
Imminent death	When caregivers thought that the child was very sick and about to die and feared the costs of transporting the dead body home	5
Chemotherapy side effects	When caregivers felt that chemotherapy made the child sicker	5
Unpleasant therapeutic procedures	When caregivers felt the therapeutic procedures were too unpleasant for their liking	3

For some caregivers, other responsibilities and social obligations competed with the care of the child.

> "My wife was almost due and she needed to go to the hospital so I became confused and left," said caregiver number 1, looking away and silent for a moment.

Many caregivers said they regarded traditional and spiritual healers as alternatives to the medical care, especially in the context of disease progression and perceived poor prognosis.

> "Ever since we left the hospital, we have been giving him herbal medicine and that's what is keeping him healthy. We even planted it ourselves and so it doesn't run out," said caregiver number 4.

Some caregivers reported feeling discouraged at the thought that cancer is incurable, often from conversations with other caregivers and observing other children who relapsed or progressed and died.

> "This disease does not cure; so even when we were taking care of him, we knew that he was going to die," said caregiver number 17, shaking her head.

Occasionally, caregivers withdrew their children from treatment because they felt the child was very sick and death was imminent and preferred the child dies at home to avoid the inconvenience of transporting the body. They either took the child away from hospital without asking for an official discharge or they did not to bring them back when the review dates were due.

> "I saw other children dying and I feared mine too would die at the hospital and I struggle bringing the body. So, I decided to bring him early so he dies at home," said caregiver number 10, keeping silent for some moments and folding her lips.

Yet, on the other hand, some caregivers said they thought that their children did not need any further treatment, since they looked fine.

> "We saw that she was well and so we decided to stay at home," said caregiver number 5.

Some caregivers also got concerned by the treatment side effects, they saw the children suffer and this motivated their decision to abandon treatment.

> "From home she would be talking, walking and eating but after giving her drugs, she would fail to eat, get mouth sores and diarrhea. That one made me hate going back," said caregiver number 16.

4 | DISCUSSION

Our study found that financial difficulties, other obligations, child falsely appearing cured, preference for alternative treatments, belief that cancer was incurable, fear that the child was about to die, and fear of chemotherapy side effects were the main reasons for treatment abandonment.

The lack of money for food, transport, and other necessities was the most common contributor to treatment abandonment among our children. This is not surprising, as Uganda's population is 74% rural,[18] with limited economic activities. Most people are subsistent farmers and spend most of their time growing food for survival. Quite often, the family benefactor is the one taking care of the child in hospital, thereby, cutting off family income abruptly with disastrous consequences for the sick child and the rest of the dependents.

Much as some meals are provided to sick children and their attendants during their hospital stay and chemotherapy and supportive drugs are free, these do not seem adequate, because money is required to meet other treatment-related costs. Money is also required for transport and lack of it is likely to discourage families that have to make repeated visits, usually for several months or even years. Financial difficulties have been reported as a reason for treatment abandonment in other studies, especially in the developing world,[10,19,20] and low social economic status has been previously identified as the most important predictor of treatment abandonment.[9,21] At UCI in Kampala, Uganda, where money for meals and transport was provided, treatment abandonments were indeed reduced to below 10%.[22]

As in previous studies,[14,23] we found that caregivers had other commitments and obligations and faced difficulty dividing their attention between other responsibilities and the care of their sick children. This is especially so if the other commitments need further financial expenses and the parent staying in hospital with the sick child is the family bread winner. Uganda is a country with a high total fertility rate of 5.6 children per woman of child-bearing age,[18] so families tend to be large, with parents of limited financial means.

Children with cancer tend to be admitted with severe symptoms, which resolve quickly after initial treatment. Most families, who are financially hard-pressed with so many other obligations, may see their children appearing healthier and no longer a priority. This has also been previously described in other studies[10,24,25] as a cause for treatment abandonment, as caregivers shift their attention to more immediate financial and social obligations.

As in our study, other studies[23,26] have described preference for other modalities of treatment among the commonest reasons caregivers report for abandoning treatment. In this community, as in many others in Africa, sickness is inherently looked at as both a physical and a spiritual problem. Communities are often convinced that there are spiritual explanations for physical disease symptoms and consult spiritual healers and herbalists for answers.[27] Children may be taken for alternative treatment before, during, and after visiting the hospital, especially if the former are cheaper and within their vicinity.

In conclusion, seeking care for children with cancer involves a lot of expenses, and families with limited income find it expensive and out of reach. In LMIC, communities and health systems are still focused on acute febrile illnesses that need short-term medical attention. Chronic illnesses, including cancer, which require repeated hospitalizations create a problem that the health system and the community in the LMIC are not yet well attuned to.[28,29] Consequently, our study shows that caregivers left alone to take care of their chronically sick children eventually get overwhelmed with economic difficulties, leading some to abandon the treatment. Caregivers, with limited resources and many dependents and who falsely think that their children are cured, are likely to abandon medical treatment and choose alternative therapies that are cheaper and easily procurable within their communities.

We recommend that the problem of treatment abandonment be approached with empathy and support, rather than blame, as most of it results from reasons beyond the caregivers' control. In particular, on top of the free cancer diagnosis and treatment, the government should provide financial support for transport and upkeep costs to caregivers or find philanthropies to do so. Healthcare-related costs, like radiological and laboratory investigations, should be provided free of charge to patients by the healthcare system.

We further recommend that psychotherapists and peer educators be employed to deal with the social and psychological aspects of cancer treatment and identify caregivers with abandonment ideation and avert it before actual treatment abandonment takes place.

The study was limited by the failure to make contact with the majority of the caregivers who had abandoned treatment, which likely caused a selection bias. The strength of the study was the success of recruiting caregivers from across a large geographical area who agreed to be interviewed face-to-face in their homes.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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